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ORIGINAL ARTICLE

Patient perspectives on treatment and prevention of recurrent urinary tract infections: a focus group study

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Abstract

Introduction and hypothesis We sought to understand factors that are important to patients for the management of recurrent urinary tract infections (UTI) during both an acute episode and for the prevention of future episodes.

Methods This was a qualitative study with focus groups in women with recurrent UTIs. Participants filled out information about prior recurrent UTI treatment and the Belief about Medicines Questionnaire (BMQ). Each 90-minute focus group was moderated by a nonphysician psychologist. Line-by-line coding of each transcript by three independent physicians was used to develop emergent concepts and themes using Grounded Theory methodology.

Results Twenty-six women participated in six focus groups. The average age of participants was 62 years and 77% were post-menopausal. All women had already tried multiple prevention strategies for their recurrent UTIs. The average BMQ-specific scores indicated a net positive attitude toward medicines specifically prescribed for recurrent UTI prevention. Several themes emerged from the focus groups. First, patients wanted providers to acknowledge the high burden imposed by frequent interactions with the health care system for the management of recurrent UTI. Second, patients wanted earlier access to providers knowledgeable in the management of this condition. Third, patients wanted to self-manage their condition through a structured treatment plan with support from their providers. Finally, patients wanted greater emphasis on education and prevention strategies to reduce their antibiotic intake.

Conclusions Patients with recurrent UTI want more efficient workflows, a framework that promotes self-management in partnership with their providers, and a greater emphasis on prevention.

Keywords Antimicrobial stewardship · Health-related quality of life · Patient empowerment · Preventative medicine · Self-management · Urinary tract infections, prevention, and control

Introduction

Urinary tract infections (UTI) are the most common bacterial infections diagnosed in the community and afflict women more than men [1, 2]. Almost 50% of women will experience at least one UTI episode in their lifetime, and multiple factors can increase the risk of recurrence [3]. Recurrent UTI is defined as two or more episodes of symptomatic UTI over six months or three or more episodes of symptomatic UTI over one year [4–6].

Previous qualitative studies on UTI have focused on the patient experience during acute episodes. These studies show the debilitating effects of acute symptoms and the impact that even one episode of UTI can have on a patient's quality of life [7–10].

In the era of antibiotic stewardship, studies have also explored patients' attitudes toward antibiotics for UTIs [11–13]. In a focus group study of women with recurrent UTIs, patients expressed fear regarding the potential harm of frequent antibiotic use and felt that health care providers were not addressing their concerns adequately [14].

Recent evidence-based guidelines on the management of patients with recurrent UTIs place emphasis on non-antibiotic prevention strategies [15, 16]. However, little is known

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about patients' experiences with prevention of recurrent UTI, and insight is scarce on the patient journey beyond the acute episode.

With a goal of building a more patient-centered care model, our objective was to understand what factors are important to patients in their decision-making for the management of recurrent UTIs during both an acute episode, and for the prevention of future episodes.

Materials and methods

Participants for this focus group study were recruited from urogynecology and urology practices of the Hospital of the University of Pennsylvania following IRB approval (protocol #852327). Inclusion criteria were women aged 18 and older with the diagnosis of recurrent culture-proven UTIs defined as two or more symptomatic episodes over six months or three or more symptomatic episodes over a year [4–6]. Exclusion criteria included patients with known anatomical anomalies of the urinary tract, diagnosis of kidney stones in the last year, pregnancy, poorly controlled diabetes (HbA1c > 9), current immunosuppressive or steroid medication therapy, practice of self-catheterization, neurological disorders known to affect the lower urinary tract, history of genitourinary malignancy or pelvic radiation, and non-English-speaking patients.

Questionnaires

Prior to focus group participation, all patients provided information about their previous recurrent UTI treatments and completed the Belief about Medicines Questionnaire (BMQ). The BMQ is a validated questionnaire that assesses patients' beliefs about medications in "general" (harm and overuse subscales). Scores lower than 12 on the harm and overuse subscales indicate that patients do not perceive medicines to be harmful to their health generally. The BMQ also has a "specific" component (necessity and concern subscales), which assesses patients' beliefs about medications prescribed for a "specific" chronic condition [17, 18]. A necessity score greater than a concern score indicates that patients perceive greater benefit than harm for their specific medications. In this study, we asked patients their beliefs about medications that they used specifically for recurrent UTI prevention.

Focus groups

The focus groups were conducted in a semi-structured format and moderated by a trained psychologist with experience in qualitative research. Each focus group lasted for about 90 minutes and the group size was limited to four to five patients owing to the sensitive nature of the topic (including the role of sexual activity) and to facilitate adequate discussion.

We developed a moderator guide designed to explore participants' experiences with recurrent UTI treatment and prevention and factors that influenced their choices (see appendix for a sample moderator guide). Discussion prompts on recurrent UTI addressed topics such as patients' current knowledge or beliefs about the condition, the impact on quality of life, the type of interactions with providers for acute episodes and prevention, perspectives on different management strategies, and the challenges in finding effective treatments for acute episodes and prevention. Following each focus group, transcripts were reviewed, and changes were made to the moderator guides to refine discussion points. Focus groups were conducted until saturation of themes was identified. All sessions were audio recorded and transcribed verbatim.

Each focus group transcript was uploaded onto NVivo 12 (QSR International, released 2017) and three independent researchers, who were familiar with the project but did not conduct the focus group, performed line-by-line coding. Codes were then reviewed and using an iterative process, codes were grouped together to determine themes and emergent concepts using Grounded Theory methodology [19]. Illustrative quotes of each concept and theme are presented. Descriptive statistics were used for participant characteristics and questionnaire data.

Results

Twenty-six women with recurrent UTIs participated in six focus groups. The average age of the subjects was 62 years and 76.9% were post-menopausal (Table 1). Overall, 73.1% of subjects identified as white and 19.2% as Black or African American. Approximately 65% of women reported sexual activity in the last year and 39% reported a history of anxiety. The average number of years between recurrent UTI onset and diagnosis by a provider was five years.

All participants were currently on, or had already tried, multiple prevention modalities for their recurrent UTIs, including lifestyle or behavioral measures, over-the-counter products, and prescription treatments. The average BMQ scores for a belief in harm and overuse of medicines were both low, suggesting that patients had an overall positive perspective on medications in general. The average BMQ specific necessity score was 17.5 and concerns score was 13, indicating a net positive attitude toward medicines specifically prescribed for recurrent UTI prevention.

We identified four emergent concepts from our focus groups. Concepts, themes, and illustrative quotes are listed (Table 2).

Table 1 Baseline characteristics of participants

	Focus group participants, (*n*=26)
Age, median (IQR)	62 (14.5)
Body mass index, median (IQR)	22 (7.3)
Post-menopausal, % (*n*)	76.9 (20)
Education, % (*n*)	
Less than high school	0
High school	7.7 (2)
Some college	7.7 (2)
Graduate from college or university	34.6 (9)
Graduate or professional school after college/university	50 (13)
Race, % (*p*)	
American Indian or Alaska Native	0
Asian or Asian American	3.8 (1)
Black or African American	19.2 (5)
Native Hawaiian or Other Pacific Islander	0
White	73.1 (19)
Other	3.8 (1)
Ethnicity, % (*p*)	
Hispanic or Latino	7.7 (2)
Not Hispanic or Latino	92.3 (24)
Income, % (*p*)	
Less than $25,001	0
$25,001–$50,000	7.7 (2)
$50,001–$100,000	19.2 (5)
Greater than $100,000	46.2 (12)
Prefer not to answer	26.9 (7)
Employment, % (*n*)	
Unemployed	15.4 (4)
Part-time	7.7 (2)
Full-time	30.8 (8)
Retired	46.2 (12)
Living with a partner or spouse, % (*n*)	73.1 (19)
Sexually active in the past year, % (*n*)	65.4 (17)
Years between recurrent UTI[b] onset and diagnosis, median (IQR)	5 (7)
Prevention strategies currently on or tried previously, % (*n*)	
Lifestyle or behavioral changes	88.5 (23)
Over-the-counter products	84.6 (22)
Prescription treatments	80.8 (21)
None of the above	0
Diagnosis of anxiety, % (*n*)	38.5 (10)
Diagnosis of diabetes, % (*n*)	11.5 (3)
Most recent HbA1c, median (IQR)	5.9 (1.3)
Any history of abdominal or vaginal surgery, % (*n*)	57.7 (15)
Total number of pregnancies, median (IQR)	2 (2)
Vaginal deliveries, median (IQR)	2 (2)
Cesarean sections, median (IQR)	0 (1)
Belief about medicines questionnaire, median (IQR)	
General—overuse	10 (6)
General—harm	7 (3)
Specific—necessity	17.5 (5)
Specific—concerns	13 (3)

IQR interquartile range, *UTI* urinary tract infection

Multifaceted burden of recurrent UTIs

First, patients wanted providers to acknowledge the high burden imposed by recurrent UTI episodes on their physical, mental, and sexual health. In describing the severity of her urinary symptoms, one patient stated, “it is so debilitating to have that pain and to sit on a toilet until that pain goes away.” Another patient described how recurrent UTIs have caused significant anxiety even in between acute episodes. “There is a constant concern, an underlying anxiety, … that it could strike at any time.” Some patients described how recurrent episodes of UTI were affecting their work. “How do I leave my office for two hours to get a test? Tell an executive committee of all men that I have to leave again?”

Others described the impact of recurrent episodes on leisure time activities. “I don’t want to take a trip because what if I take a trip and I get a UTI and can’t drop off urine, can’t get antibiotics, and can’t treat it.” Several patients described how the fear of a UTI was preventing them from being sexually active with their partners. “Every time we are intimate, I am so freaked out and scared that I’m going to get a UTI … I can’t enjoy this beautiful thing with my partner.” Some patients also described the adverse impact of recurrent episodes of UTI on their relationship. “My husband’s reaction was, ‘so I gave this to you.’ We both felt awful. We both felt as if we were doing something wrong.”

Patients also described the burden imposed by the need to frequently interact with the health care system for the management of UTI episodes. One patient said, “the same telehealth wouldn’t give me antibiotics back-to-back if the first one didn’t work, so then I would hop telehealth programs.” Patients also expressed frustration with delays in care when they were suffering from an acute episode. “I call the doctor’s office when I get symptoms and sometimes, they get back to me within two to three hours, but other times they forget … It’s not a priority for anyone but me.” Additionally, participants described the burden imposed by urine tests and how this can contribute to delayed treatment. “… I drop a sample off. But there is such a time lag between the time [my provider] gets the results. I have to suffer for at least 24 hours and sometimes longer if it’s the weekend.”

Access to knowledgeable providers

Study participants identified how a lack of providers knowledgeable in recurrent UTIs delayed their diagnosis of the condition and served as a major barrier to receiving appropriate treatment. A common experience among participants was years of being treated with antibiotics for each acute episode, regardless of how frequently they occurred. For example, one patient said, “my nurse practitioner … said every time you have an infection, we will give you an antibiotic. I was the one who has become more assertive about it. This can’t be normal.” Another patient described a similar experience. “I had a doctor who would just send me antibiotics every time I got symptoms, but I would get symptoms every six weeks. Antibiotics stop working when you use them every six weeks for 15 years.” A few patients felt that some providers had even blamed them for repeated episodes. On patient stated that her provider had made her feel “dirty,” whereas another stated, “I always felt that I’m doing something wrong or there is something wrong with me.”

Several patients wished they had received earlier referral to a specialist because they believed a knowledgeable provider would have made the diagnosis of recurrent UTI sooner. One participant shared that “having a provider who is familiar with female UTIs and deals with this regularly is helpful.” A specialist also gave participants access to preventive treatments. “My urogynecologist got me on my current prevention regimen of D-mannose and vaginal estrogen, which seems to work.” This theme intersected with their desire to be educated about their condition. “They taught me so much about this subject matter and why my body is doing things.” Patients also valued empathy from their providers. “The care and concern from my urogynecologist resonated with me.”

Desire for self-management

Patients anchored their desire for self-management in the knowledge that they could accurately self-diagnose their episodes of UTI. One patient shared that “I can tell you that every time I have thought I have had a UTI, it has been a UTI. 100% of the time I have been right.” Although many patients were confident about their ability to diagnose an acute episode of UTI, they still wanted to manage these episodes in partnership with a provider. “I appreciate that my doctor has trusted me to know when I need to get a lab test. I don’t have to persuade her. I appreciate that respect.”

Importantly, participants wanted to take an active role in managing their condition. Several patients recounted that they were already trying self-care practices at home (generally with little success) when they finally talked to a provider and developed a structured regimen that worked. “I take azo and still drink a lot of water. I didn’t know about azo until talking to the doctor. Boy, did that make a difference.” Most patients also recognized that prevention plans frequently involved multiple interventions. “After talking to my doctor, I’m trying to use a multifactorial approach with methenamine with vitamin C, cranberry, D-mannose, drinking a lot of fluids, and not rushing in the bathroom.” Patients are also keenly aware of the side effects of treatments and relied on their providers to guide them in choosing appropriate treatments. For example, one patient recalled, “when I first started taking the [methenamine], it seemed like it was working. I then tried to scale it back to try to minimize my

Table 2 Emergent concepts, themes, and illustrative quotes

Emergent concept	Themes	Illustrative quote
Multifaceted burden of recurrent UTIs	Quality of life impact	"It is so debilitating to have that pain and to sit on a toilet until that pain goes away. It is the most God-awful thing."
		"It is always in the back of the mind, what if I get one? There is a constant concern, an underlying anxiety, a hyperawareness that it could strike at any time."
		"I felt constant frustration trying to understand what my problem was and how to get it fixed, while also working. How do I leave my office for 2 hours to get a test? Tell an executive committee of all men that I have to leave again?"
		"UTIs prohibit me from living as wide as I would like to. I'm always afraid I am going to get one. I don't want to take a trip because what if I take a trip and I get a UTI and can't drop off urine, can't get antibiotics, and can't treat it."
		"I just got married and literally the day after our wedding night, I got a UTI. I can't even enjoy intimacy with my husband and he can't enjoy it. Every time we are intimate, I am so freaked out and scared that I'm going to get a UTI. It is really sad. I can't enjoy this beautiful thing with my partner."
		"My husband's reaction was, 'so I gave this to you.' We both felt awful. We both felt as if we were doing something wrong."
	Too many points of contact with the health care system for disease management	"I used to call a telehealth to get antibiotics whenever I started to feel symptoms. However, the same telehealth wouldn't give me antibiotics back-to-back if the first one didn't work, so then I would hop telehealth programs. I know that is problematic, but all I wanted was to feel better because these infections are awful."
		"I call the doctor's office when I get symptoms and sometimes, they get back to me within two to three hours, but other times they forget and I have to call again the next day. It's not a priority for anyone but me."
		"I contact my urologist, she gives me a script for Labcorp and I drop a sample off. But there is such a time lag between the time she gets the results. I have to suffer for at least 24 hours and sometimes longer if it's the weekend."
Access to knowledgeable providers	Recognition of recurrent UTI as a condition distinct from single episodes of UTI	"My nurse practitioner said it was not anything to be worried about. She said every time you have an infection, we will give you an antibiotic. I was the one who has become more assertive about it. This can't be normal. There has to be a reason this keeps happening."
		"My PCP was getting frustrated with me, having to constantly ask me to go somewhere to give a urine sample or to get a prescription."
		"I had a doctor who would just send me antibiotics every time I got symptoms, but I would get symptoms every 6 weeks. Antibiotics stop working when you use them every 6 weeks for 15 years, so I finally saw a urogynecologist."
		"At the primary care or urgent care level, I always felt that I'm doing something wrong or there is something wrong with me."
	Early referral to a specialist	"Finally meeting a urogynecologist and understanding that just being a woman puts me at risk was invaluable information. Having a doctor that doesn't make me feel like I'm dirty is invaluable."
		"Having a provider who is familiar with female UTIs and deals with this regularly is helpful. Going to a provider who doesn't know a thing about women doesn't help. It is helpful to have a doctor who has treated this before and can tell me that her patients have tried X, Y, or Z or that this is a common problem. This kind of provider just has more resources to draw on."
		"My urogynecologist got me on my current prevention regimen of D-mannose and vaginal estrogen, which seems to work."
		"When I got the chance to go to the urogynecologist, they taught me so much about this subject matter and why my body is doing things."
		"The care and concern from my urogynecologist resonated with me."

Table 2 (continued)

Emergent concept	Themes	Illustrative quote
Desire for self-management	Providers should trust patient self-diagnosis during acute episodes	"I can tell you that every time I have thought I have had a UTI, it has been a UTI. 100% of the time I have been right."
		"Every time I have gone to my doctor with symptoms in the past, I've been correct about an infection, so she is comfortable with the procedure we use now. It's a very smooth process now."
		"I appreciate that my doctors have trusted me to know when I need to get a lab test. I don't have to persuade her. I appreciate that respect. That makes a big difference. That give me a half-day head-start."
		"I appreciate that when I call in, I get a response before the end of the day and the doctors trust that I know what is going on with my body because this is a recurring problem and I know the symptoms of an infection."
	Structured management plan with provider guidance	"I take azo and still drink a lot of water. I didn't know about azo until talking to the doctor. Boy, did that make a difference."
		"I try to drink a lot of water and take a probiotic at home. Also, my doctor recently put me on [methenamine] twice a day for six months. I believe these are all helping."
		"After talking to my doctor, I'm trying to use a multifactorial approach with methenamine with vitamin C, cranberry, D-mannose, drinking a lot of fluids, and not rushing in the bathroom."
		"When I first started taking the [methenamine], it seemed like it was working. I then tried to scale it back to try to minimize my medication usage. I tried some of the behavioral practices instead of relying on the medication to work. However, when I scaled back the [methenamine], within six months, I had a UTI. So now I'm back on it, after talking to the doctor. I try to be religious about it and regular about my personal hygiene and behavioral stuff because it's all been working."
	Reduce antibiotic use	"I think it is terrible that we throw antibiotics at this problem instead of finding a solution."
		"Each doctor just treated me because doctors are there to treat. Very few doctors discuss prevention options to diminish the frequency of these infections. I would be happy enough with just diminished frequency of these infections."
		"I started on daily prophylactic antibiotics but developed a lot of resistance so was put on [methenamine] for a few months. That seemed to work. Taking too many antibiotics I do care about because I had urosepsis and was hospitalized due to my antibiotic resistance."
		"I had pyelonephritis twice. Let me tell you. You might feel bad with a UTI but when you are on IV cipro and IV fluids and you can't lay on your back because of your kidney infection, that is truly bad."
Greater focus on prevention	Education about the disease	"I feel that if a woman goes to her doctor, whether it be primary care, Ob/Gyn, or a specialist, and is positive for a UTI, that is when the education should start. The first episode should trigger the education."
		"More education would be helpful. If I had known where this comes from and what I can do about it, it would have been better. For the first 10 years when I had this, if my providers hadn't just looked at this like the common cold and some people just get it sometimes, my experience would have been different."
		"Just knowing this is a common condition among women. Knowing that there are specific antibiotics for specific bacteria. If I had known all of this in the beginning, I could have saved myself a lot of grief. I didn't want to learn all of this from experience."
	Evidence-based and convenient prevention methods	"You Google stuff but there is just so much information out there and it's hard to decide what is good and what is bad information."
		"Anything that would work consistently and be convenient would be my ideal prevention."

Table 2 (continued)

Emergent concept	Themes	Illustrative quote
		"When I take two [methenamine] a day, I know I'm safe. I can travel wherever I want to go. I don't have to find a pharmacy on a Saturday evening to get antibiotics."
		"I consider two factors: total protection from UTIs and convenience. My life is really hard. I have a demanding job. If I can just swallow a pill twice a day, I'll happily do it. I want the quality of life."
		"I feel like any advice that is given should be evidence based. It should not be guessing and I think a lot of it is guessing."

UTI urinary tract infection

medication usage….within six months, I had a UTI. So now I'm back on it, after talking to the doctor."

Greater focus on prevention

Although patients wanted faster access to antibiotics for the treatment of acute episodes, they expressed concern that they were taking too many antibiotics. One patient said, "I think it is terrible that we throw antibiotics at this problem instead of finding a solution." Patients expressed frustration that they had been repeatedly prescribed antibiotics without any discussion of ways to prevent UTIs. "Very few doctors discuss prevention options to diminish the frequency of these infections." A few participants even recounted the serious consequences they experienced owing to overtreatment with antibiotics. "… I had urosepsis and was hospitalized due to my antibiotic resistance."

An important theme that emerged under the concept of prevention was patients' desire to learn more about their condition. One participant stated, "I feel that if a woman goes to her doctor…and is positive for a UTI, that is when the education should start." Several participants expressed how education about the causes of recurrent UTI would have empowered them to grapple with their condition better. "If I had known where this comes from and what I can do about it, it would have been better." Another patient said, "if I had known all of this in the beginning, I could have saved myself a lot of grief. I didn't want to learn all of this from experience."

Patients specifically stated that they wanted their providers to recommend evidence-based prevention strategies. For example, one participant said, "you Google stuff but there is just so much information out there and it's hard to decide what is good and what is bad information." Patients described how effective preventive strategies have improved their daily quality of life. "When I take two [methenamine] a day, I know I'm safe. I can travel wherever I want to go. I don't have to find a pharmacy on a Saturday evening to get antibiotics." However, patients also wanted prevention strategies that fit with their lifestyle. "I consider two factors: total protection from UTIs and convenience. My life is really hard. I have a demanding job. If I can just swallow a pill twice a day, I'll happily do it."

Discussion

Our study sought to understand the journey of a patient with recurrent UTI not only during acute episodes but also in-between episodes when they are not experiencing UTI symptoms. Several patient-centered concepts emerged. First, recurrent episodes of UTI have a significant negative impact on the quality of life of patients. Patients described the need to frequently contact a health care provider for the management of recurrent episodes being a considerable source of frustration. Second, delayed access to providers knowledgeable in the management of recurrent UTI had delayed their diagnosis and implementation of prevention strategies. Third, patients wanted to participate in the management of their condition (self-management) in partnership with their providers. They wanted providers to trust their ability to self-diagnose an acute episode and to develop a structured plan for prevention that was evidence-based, effective, and convenient to their lifestyle. Finally, patients were keenly aware of the risks of antibiotic overuse and wanted providers to focus on disease education and preventive treatments.

A cross-cutting idea was inefficient workflows that resulted in frequent interactions with the health care system. Patients reported that many providers failed to understand the impact that delays in urine tests and antibiotic prescriptions for acute episodes had on their everyday lives. Patients were also frustrated with the long interval (median of five years) between the onset of recurrent UTI symptoms and the final diagnosis, which patients attributed to delayed referral to a specialist.

Interestingly, providers who take care of women with recurrent UTI are also frustrated by inefficient workflows. A recent focus group of urogynecologists reported that providers feel that they and/or their staff spend considerable nonbillable hours dealing with UTI-related problems [20]. Some providers have tried to streamline the workflow of uncomplicated episodes of UTI by using a telephone triage system that reduces testing and the need to physically visit a provider [21]. These findings suggest that a management paradigm that includes more efficient processes for ordering

urine tests, prescriptions, and referrals will likely benefit both patients with recurrent UTI and their providers.

Self-management has been shown to be an important concept for many chronic diseases, including interstitial cystitis/painful bladder syndrome, another chronic bladder condition [22, 23]. In our focus groups, patients with recurrent UTI demonstrated several characteristics that are rooted in the principles of self-management: problem-solving, decision-making, resource utilization, patient–provider partnerships, action planning, and self-tailoring [24].

For example, in our study, patients with recurrent UTI demonstrated problem-solving skills by identifying that frequent antibiotic use was harmful to their health. Decision-making was noted through their net positive attitude toward preventive medications on the BMQ and active efforts to seek out ways to prevent UTI episodes. Patients used a variety of resources, including internet research and discussion with family and friends, to identify behavioral practices and over-the-counter medications that could help prevent UTIs. Action planning was noted in patients' willingness to try multiple strategies to prevent UTI episodes, even if some did not work initially. Finally, patients self-tailored their prevention plan by working in partnership with their providers to minimize the number of prevention prescription medications they were taking. These findings provide a useful framework for how clinicians can support patients with recurrent UTI in achieving self-management through patient education, more efficient workflows, and evidence-based prevention options that empower and engage patients in their own care.

Patients also expressed how the lack of attention given to the prevention of recurrent UTIs has contributed to their negative experiences with this condition. Several patients stated that their fear and anxiety about the pain of recurrent episodes had prevented them from fully participating in work and leisure time activities. Patients expressed anger and frustration when dealing with providers who did not offer preventive treatments and a sense of relief when they learned that there may be an underlying cause of their condition. The significant negative impact of recurrent UTI even in the absence of acute symptoms underlies the importance of early diagnosis and implementation of preventive treatments to prevent breakthrough episodes. The relief that patients experienced when learning about causes and strategies to prevent UTI episodes highlights the important role that patient education plays in reducing anxiety and strengthening patient–provider relationships.

The strengths of this study include using a moderator who is a trained psychologist familiar with the field but who was not involved in data analysis. We administered the validated BMQ questionnaire before focus group participation, allowing us to capture patient attitudes prior to any group biases that could have influenced patient responses. The limitations of this study include a small cohort size with predominantly white, college-educated participants, which may limit the generalizability of the findings. Additionally, all participants were recruited from a tertiary academic center where they had seen a specialist for this condition at least once. Patients in different practice settings may have different care experiences and goals.

In conclusion, patients with recurrent UTI want more efficient workflows, a framework that promotes self-management in partnership with their providers, and a greater emphasis on prevention. These findings can inform the development of a patient-centered approach to managing recurrent UTIs.

Appendix 1: sample moderator guide

A urinary tract infection, or UTI, is a bacterial infection of the urethra, bladder or the kidney. Most patients get an infection of the bladder or the urethra. Kidney infections are called pyelonephritis. Recurrent UTI means getting several UTIs. How many UTIs is too many? A common definition for recurrent UTI is getting two or more UTIs in 6 months or three or more UTIs in 1 year. Today, we would like to ask you specifically about how you prevent and treat recurrent UTIs.

1. What are some reasons you think women get recurrent UTIs?
2. We want to understand what measures or actions, if any, each of you takes to *prevent* an episode of UTI. Can you share what you have tried prior to today?
3. We now want to understand what makes you choose one prevention measure over another. What factors into your decision?
4. What would be your ideal treatment plan for preventing recurrent UTIs?
5. What are your very first emotions once you start to feel symptoms of a UTI episode come on?
6. Now we would like some of you to share what you do once you start to feel symptoms of a UTI.
7. Do your UTI symptoms vary from episode to episode or are they generally consistent?
8. How often has it happened that you thought you were getting a UTI but it turned out you did not have a UTI? How did you manage in those cases?
9. How long does it generally take for your symptoms to start improving once you start antibiotics for an episode?
10. What resources have you used to make decisions about prevention and treatment in the past?
11. What kind of context or information did your doctor initially provide regarding your diagnosis of recurrent UTIs?
12. Now let's take a step back and think about recurrent UTIs more globally. We want to understand the impact that your recurrent UTIs have had on your life.

13. Thinking about managing recurrent UTIs through the current health care system, what frustrates you or alternatively what works well?
14. Are there any other things that we might have missed that would be important to know about your experiences with recurrent UTIs?

Authors' contributions S. Agrawal: project development, data analysis, manuscript writing, manuscript editing; H. Harvie: project development, data analysis, manuscript editing; L. Flick: data collection; R.B. Parikh: data analysis, manuscript editing; U.U. Andy: project development, data analysis, manuscript editing; L. Arya: project development, data analysis, manuscript editing.

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Declarations

Conflicts of interest L Arya has received speaker and education fees from Urovant Sciences. None of the other authors has any conflicts of interest to report.

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